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Peripheral Arterial Disease: Public and Patient Awareness in the Netherlands

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Objective. To determine critical issues for future awareness programmes on peripheral arterial disease (PAD).

Design. National Dutch survey.

Materials and methods. A representative sample of 1294 members of the general population, and 281 patients with PAD from the Capi@home database were administered a questionnaire concerning awareness of PAD.

Results. The response rate was 81% for the general population and 78% for patients with PAD. The familiarity with PAD terminology and symptoms amongst the general population was low. Few patients (20%) were aware that PAD was a disease of arteries. Amongst both the general population and the patient populations, PAD risk factors identification was low: hypertension (4% versus 0%); hypercholesterolaemia (9% versus 12%), diabetes (2% versus 8%), and smoking (27% versus 52%). Knowledge was moderate in both populations about treatment with exercise, but low for smoking cessation. The general population was unaware of the central role of general practitioners in the treatment of PAD.

Conclusions. The awareness of symptoms, risk factors, and treatment options for PAD is low. Both population and patients needed only minimal information to relate PAD to other atherosclerotic diseases. Based on the results of this survey the Dutch Platform of Peripheral Arterial Disease together with the Dutch Heart Foundation are initiating the first awareness campaign on atherosclerosis.

Key Words: Peripheral arterial disease; Awareness; Risk factors; Intermittent claudication; Atherosclerosis.

Introduction

In 1998 the Dutch Heart Foundation, in collaboration with the Dutch Society for Vascular Surgery and the Dutch Society for Vascular Patients, published a report called 'Vaatchiënten in beeld' (Vascular patients in the picture).¹ The report painted a picture of the situation of vascular care in the Netherlands in 1998. With respect to peripheral arterial disease (PAD), the report contained recommendations on making improvements in primary and secondary risk factor management, increasing

general practitioner and vascular specialist care, and on developing an exercise therapy infrastructure. Some of these recommendations have recently been implemented, whilst others are currently being developed. One of the report's main conclusions was that the awareness of PAD (e.g. its cause, prevention and treatment) amongst the general population as well as amongst patients with PAD should be increased.¹ The combined prevalence of symptomatic and asymptomatic PAD in the population of 55 years and over in primary care settings in the UK, USA and the Netherlands is 18–23%.^{2–4} The overall ageing of the population, due to the arrival of the 'baby boom generation', increases the percentage of patients with PAD. Despite these increases, no actions have so far

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been initiated to start an awareness or educational programme on PAD.

Patients with symptomatic PAD have at least a 30% risk of death within 5 years rising to almost 50% within 10 years, resulting primarily from myocardial infarction or stroke. Together these are responsible for 60 and 12% of total mortality, respectively.⁵ These risks are highest for patients requiring surgery, but even individuals with an ankle-brachial index below 0.9, who do not seek medical care, have a 2–5-fold increased risk of fatal or non-fatal cardiovascular events compared to the normal population.^{5–7} The development and progression of PAD is strongly influenced by vascular risk factor management and life style changes. Risk factor management in primary care settings focuses mainly on the detection and treatment of diabetes, hypertension and hypercholesterolaemia. Lifestyle changes consist of smoking cessation, as the single most powerful risk factor associated with the aetiology and clinical progression of PAD.^{8,9} Exercise therapy is the primary conservative treatment when walking is impaired.^{10,11}

Early identification of the disease could lead to earlier vascular risk-factor modification and result in a subsequent decrease in progression of PAD as well as a reduction in cardiovascular events.¹² Early detection depends not only on physician awareness, but also on the public being aware of symptoms and vascular risk factors.^{13,14}

The aim of this study was to assess current awareness and knowledge of PAD in the general population and amongst patients with PAD by means of two surveys.

Methods

Two surveys were performed by the Dutch Institute for Public Opinion and Market Research (NIPO) in 2003, one carried out amongst the general population and one amongst patients with known PAD. Both surveys covered topics on general knowledge of PAD terminology and symptoms, risk factors, and treatment options by personal efforts and in a medical setting (Appendix A and B). Preliminary versions of the surveys were piloted in the respective populations in order to assess their comprehensibility (cognitive debriefing) and adapted when appropriate. The pilot data have not been used in the final data collection.

Population

A representative sample of 1294 members of the general population of 18 years or older and 281

patients with PAD above the age of 35 years in the Netherlands was derived from the Capi@home database. The participants gave informed consent for the anonymous use of the data. For inclusion in the patient population, patients had to have been diagnosed with PAD by a general practitioner or vascular surgeon.

The Capi@home database contains extensive information on general topics as well as on diseases of more than 100,000 inhabitants in the Netherlands and was used for surveys on public opinion. The survey participants received the digitally transmitted questionnaire on a personal computer at home, which they completed and returned via a direct modem. In the Netherlands, 79% of all households have a personal computer with internet access.

In order to obtain a representative sample from both populations, demographic frequency matching was carried out in respect of the following variables: age, sex, income, family size, ethnic background, education and postcode. The database is over-sampled in the categories of respondents with low personal computer ownership, particularly amongst older people and the less well educated. However, the size of the database enabled samples to be drawn, which were representative of both populations. The participants gave informed consent.

Analysis

The sample size was calculated on the basis of the maximum width of the 95% confidence interval around the observed point estimates. In order to obtain a width of less than 7.5% (one-sided margin of error 3.75%) for the estimates of the general population, at least 750 valid responses would be required and likewise, 180 from the patient population to obtain a width of less than 15% (one-sided margin of error 7.5%). Hence for sake of clarity 95% confidence intervals are not described further. Differences between groups were analysed with a chi-square test using SPSS version 11.0.

Results

Population

The response rate for the 1294 members of the general population was 81% and for the 281 patients with PAD, 78%. This resulted in 1048 and 219 valid questionnaires, respectively. The demographic characteristics of both populations are presented in Table 1.

Table 1. Demographic characteristics of the general population and patients with PAD

	General population	Patients with PAD
Sex		
Male	514 (49%)	117 (53%)
Female	534 (51%)	102 (47%)
Age distribution (years)		
18–34	332 (32%)	
35–44	405 (39%)	15 (7%)
45–54		42 (19%)
55–64	311 (30%)	51 (23%)
> 64		111 (51%)
Time since diagnosis (years)		
> 5		100 (46%)
1–5		86 (39%)
1– $\frac{1}{2}$		17 (8%)
1–6 (m)		16 (8%)
Walking distance (m)		
> 100		156 (71%)
100–30		50 (23%)
< 30		14 (6%)

Demographic information on non-respondents was not available. As expected, the majority of patients with PAD were over 55 years of age and had stage II PAD according to Fontaine (Rutherford grade I).

General knowledge about PAD terminology and symptoms in the general population

Members of the general population were asked if they were familiar with the various terms for PAD. The layman's term in Dutch, 'etalage benen' (literally 'window-shopping legs'), was recognised most frequently (by 56%). Fifteen percent had heard of 'peripheral arterial disease' and 5% was familiar with the term 'intermittent claudication'. This familiarity was higher among women ('window-shopping legs' 67%; $P < 0.0001$) and people over 55 years of age ('window-shopping legs' 72%; $P < 0.0001$). In the general population, 22% knew a relative or friend with PAD. When asked if they could identify one or more symptoms of PAD, 16% answered pain in the legs that subsides during rest (23% when a relative or friend had PAD, compared to 13% in the remainder; $P < 0.0001$) and 21% pain during walking. The sources for additional information on PAD are presented in Table 2. The difference between generations with respect to the use of internet was statistically significant ($P < 0.0001$), but even amongst elderly users, the use of internet outweighed medical books as source of information.

Table 2. Reference sources for additional information on PAD

	General population		Patients with PAD
Internet	701 (67%)		29 (44%)
	18–34 years	> 55 years	
	79%*	50%*	
Leaflet	476 (45%)		16 (24%)
Medical books	327 (31%)		
	18–34 years	> 55 years	2 (3%)
	18%*	35%*	
Doctor	28 (3%)		19 (30%)
Family/friend	26 (2%)		0
Patients association	24 (2%)		1 (1%)
Media	18 (2%)		4 (6%)
Unknown	68 (6%)		5 (7%)

* $P < 0.05$.

General knowledge about PAD terminology and symptoms in the patient population

Of the patients, 21% were aware that PAD concerns the arteries, 25% were of the opinion that the veins and the arteries were diseased. Eleven percent considered it a venous disease, and 43% did not know the localisation of PAD. Thirty percent of patients searched for additional information on PAD. These sources are depicted in Table 2.

Knowledge of risk factors in the general population

When the general population was asked to classify PAD, ranging from an innocent condition to a very serious condition, 25% classified PAD as a relatively innocent condition, 61% as relatively serious, 5% as very serious, and 9% did not know how to classify PAD at all. The aetiology of PAD was briefly explained as: 'a vascular problem causing an insufficient blood supply to the legs resulting in pain in one or both leg(s) during exercise which subsides during rest'. After this explanation the general population was asked if there might be an association between PAD and the development of systemic cardiovascular diseases. The majority (74%) assumed that there was an association between PAD and an increasing likelihood of developing cardiovascular diseases (females 80%; males 68%; $P: 0.04$). The risk factors for developing PAD that were mentioned spontaneously are detailed in Table 3.

Knowledge of risk factors in patients with PAD

After the explanation of the aetiology of PAD, the majority (77%) were of the opinion that an association did exist between PAD and an increasing risk of developing cardiovascular complications (females

Table 3. PAD risk factor recognition

	General population	Patients with PAD		Patients reported personal risk factors	
Smoking	279 (27%)	114 (52%)		74 (34%)	
High cholesterol	89 (9%)	26 (12%)		19 (9%)	
				55–64 years	> 65 years
				22%*	2%*
Hypertension	41 (4%)	0		0	
Diabetes	24 (2%)	18 (8%)		14 (6%)	
Increasing age	38 (4%)	9 (4%)		7 (3%)	
Scarce physical exercise	293 (28%)	49 (23%)		15 (7%)	
		Male	Female		
		34%*	9%*		
Runs in the family	82 (8%)	33 (15%)		29 (13%)	
Unknown	218 (21%)	23 (11%)		29 (13%)	

* P : < 0.05.

72%; males 81%; P < 0.0001). The results of the question, 'Could you name possible risk factors that increases the risk of developing PAD?', are summarised in Table 3. A significant difference was present in favour of the patients' knowledge of risk factors compared to the general population (χ^2 : 138.1; P < 0.0001).

Medical advice and treatment in the general population

If suffering pain on walking which subsides when resting, 23% of the general population said they would visit a physician immediately, and a further 75% would go later, if the complaints persisted. When asked about which medical discipline would be primarily responsible for treatment of PAD, 27% were of the opinion that a vascular surgeon would be responsible, 14% an internal medicine specialist, 12% a cardiologist and 31% said that they did not know. When requested to list possible treatment options for PAD, 29% mentioned medication, 17% surgery, 14% physical exercise, 9% angioplasty and 4% smoking cessation. Over one third (37%) were unfamiliar with any treatment. Life-style changes reported that could be undertaken to improve PAD, are depicted in Table 4. Increasing the daily amount of physical exercise was mentioned relatively often

(47%), while smoking cessation received little attention (18%).

Medical advice and treatment in patients with PAD

Of the patients with PAD, 56% smoked at the time of onset of the complaint. Of these patients who smoked at the onset of complaint, 45% continued smoking (males 33% and females 64%; P = 0.01), and 48% had quit smoking, but had smoked in the past 10 years (males 59% and females 33%; P = 0.001). Patients reported that the general practitioner had measured their blood pressure in 95%, cholesterol levels in 77%, and fasting glucose levels in 64%. After the onset of complaints, 34% of the patients reported having consulted a physician within 6 months. At the time of the interview, 50% of the patients with PAD were seeing a vascular specialist, 27% were receiving treatment from their general practitioner and 20% were not seeing a physician any more. Of the patients receiving treatment from a vascular specialist or general practitioner, 33% were also seeing a cardiologist (males 47% and females 16%; P < 0.0001) and a further 15% a neurologist. Patients reported significantly more personal measures that could be undertaken to improve PAD (χ^2 : 35.5; P < 0.0001), compared to the general population (Table 4).

Table 4. Treatment options endorsed by personal efforts

	General population	Patients with PAD
Exercise	478 (47%)	105 (48%)
Diet	331 (32%)	69 (32%)
Stop smoking	184 (18%)	66 (30%)
Medication	37 (4%)	27 (12%)
Life style	181 (18%)	28 (13%)
Unknown	259 (25%)	24 (11%)

Discussion

General knowledge on PAD terminology, symptoms and risk factors

Familiarity with the terminology regarding PAD or intermittent claudication in the general population is

low. The familiarity increased if there was a friend or relative with PAD. Similar increases in awareness have been described for relatives of patients with diabetes, but in comparison, PAD-related awareness is much lower.¹⁵ Risk factors for PAD risk factors were relatively unrecognised in both populations. Female members of the general population were more aware of risk factors for developing PAD than their male counterparts. This was reversed in the patient population, suggesting that male patients received or perceived more information.

Medical advice and treatment

The general practitioner was not identified by the general population as the central physician for managing patients with PAD. This central role should be emphasised in future awareness campaigns. There was a large difference in number of visits to a cardiologist between male and female patients. This difference could be explained by the more progressive PAD in men, but could also suggest a possible under-treatment of women.¹⁶ The relatively low prevalence of a smoking history in this survey, which in large population studies is between 80 and 90%, could be explained partially by the patients' avoidance of socially less acceptable responses.^{17,18} The relatively large number of responses relating to the improvement of diet and general lifestyle appear to be influenced by the modern 'health cult'.

Limitations of this survey

The survey results may be biased by personal interests of the respondents. However, the high response-rate would suggest that this potential bias is limited. If a respondent bias exists, this would imply that actual knowledge on PAD is even worse than this survey indicates. The methodology of the survey, based on the CAPI@home server, might account for the relatively high percentage that utilises the internet as the disease-related information resource. On the other hand the majority (79%) of the Dutch households own a personal computer with internet access, and this will continue to rise.

Awareness

Patient delay in response to symptoms, as a result of not recognising their importance, has been reported in patients with heart attack and stroke.^{19,20} Only

one third of the patients with PAD seek medical care, with a substantial delay after the start of symptoms; resulting in a negative impact on the time of onset of treatment and vascular risk factor management.⁶ This delay in treatment increases the risk of cardiovascular events and allows more rapid progression of PAD.¹²

The low familiarity of PAD and accompanying risk factors we observed in the Netherlands is concerning, and worse than internationally reported data.¹⁶ Community education in the United States and Europe on improving awareness and risk factor recognition has been shown to be effective, with educational programmes on heart attack, high blood pressure, cholesterol, PAD and stroke.^{21–25} Data on the effects of community educational programmes on clinical endpoints are meagre and inconclusive. Programmes on increasing the adherence to medication in patients with hypertension and decreasing the dietary intake of saturated fat have shown positive results, but have failed to impact on the treatment of high cholesterol and smoking.^{22–24} Despite these results, the costs of community educational programmes have been shown to outweigh the direct and indirect financial burden of these diseases on the national healthcare budget.²³ Unfortunately only isolated campaigns with respect to stopping smoking, eating healthily, and keeping fit have already been initiated in the Netherlands. In our survey, it appears that PAD is easily explained as an element of systemic atherosclerosis. Future awareness campaigns should take advantage of this knowledge and not be limited by different vascular specialists, and cross speciality boundaries to cover the full spectrum of atherosclerotic disorders.

Conclusions

The results of this survey indicate that in the general population and in patients with PAD, the general knowledge of PAD terminology, symptoms, risk factors, and treatment options by behaviour and lifestyle modification or medical treatment is sub-optimal. Community education on improving awareness and risk factor recognition has been shown to be effective, but studies of the effects of community education on clinical endpoints are needed.

Based on the results of this survey the Dutch Platform of Peripheral Arterial Disease together with the Dutch Heart Foundation are initiating the first awareness campaign, focussing on symptoms, risk

factors, life style changes, and treatment options, for atherosclerosis.

Appendix A. Abbreviated questionnaire for general population; PAD: peripheral arterial disease, IC: intermittent claudication, WSL: window shopping legs

1. Have you ever heard or read anything about PAD?
2. Have you ever heard or read anything about IC?
3. Have you ever heard or read anything about WSL?
4. Do you know anyone with PAD, IC, or WSL?
 - a. Yes (→ 5)
 - b. No (→ 6)
5. Who do you personally know with PAD, IC, or WSL?
 - a. Myself
 - b. Family member
 - c. Friend/acquaintance
 - d. Someone else (colleague etc.)
6. What do you think when you hear the term PAD?
 - a. A very innocent condition
 - b. A relatively innocent condition
 - c. A relatively serious condition
 - d. A very serious condition
 - e. I do not know
7. To what extent do you think that the assumption that the presence of vascular problems in the legs gives a higher risk of developing vascular problems in the heart and head is correct?
 - a. I agree
 - b. I disagree
 - c. I completely disagree
 - d. I do not know
8. What kind of physical complaints in your opinion are associated PAD or IC?
9. Which medical profession do you think is responsible for treating PAD?
10. What would you do if you regularly felt pain in your legs whilst walking and which subsided when you rested?
11. At what point would you consult a physician if you felt this pain in your legs?
12. Would you consider a referral by your general practitioner to a vascular specialist important?
 - a. Very important
 - b. Important
 - c. Not important

- d. Not important at all
- e. I do not know
13. Which factors do you think increase the likelihood of developing PAD?
14. In what way do you think PAD or IC can be treated?
15. What could you personally do to reduce the complaints associated with PAD?
16. Where would you seek out information on PAD?

Appendix B. Abbreviated questionnaire for patients with PAD; PAD: peripheral arterial disease

1. How long have you been diagnosed with PAD?
2. How long did you wait to visit your general practitioner after you first experienced PAD complaints?
3. In which blood vessels do you think PAD is located?
 - a. Arteries
 - b. Veins
 - c. Arteries and veins
 - d. I do not know
4. Which risk factors do you think increase the likelihood of developing PAD?
5. Which risk factors do you yourself have in the development or deterioration of PAD?
6. What might you do personally to reduce the complaints of PAD?
7. To what extent do you think that the assumption that the presence of vascular problems in the legs leads to a higher risk of developing vascular problems in the heart and head is correct?
 - a. I agree
 - b. I disagree
 - c. I completely disagree
 - d. I do not know
8. Did you smoke at the moment you developed PAD complaints?
 - a. Yes (→ 9)
 - b. No (→ 10)
9. Did you give up smoking after you developed PAD?
10. Do you currently smoke or have you smoked in the past 10 years?
 - a. I smoke
 - b. I have smoked in the past 10 years
 - c. I have smoked, but stopped >10 years ago
11. Who at the moment is your PAD physician?

12. Which of the following items have been measured by your general practitioner?
 - a. Blood pressure
 - b. Fasting glucose
 - c. Cholesterol
 - d. None of the above
13. Has your ankle-brachial index ever been measured?
14. Has your general practitioner spoken to you about exercise therapy?
 - a. Yes (→ 15)
 - b. No (→ 16)
15. What has your general practitioner advised you to do?
 - a. To walk more
 - b. To walk more and he/she also gave me an additional brochure entitled 'exercise therapy'
 - c. Referred me to a physiotherapist for exercise therapy
 - d. I do not know
16. Has any physician ever given you antiplatelet medication?
 - a. Yes (→ 17)
 - b. No (→ 18)
17. Which medical profession has prescribed this medication?
18. How many metres are you able to walk before you have to stop due to pain in your legs?
19. Have you even been operated on the arteries in your legs?
20. Are you seeing a cardiologist for problems associated with the arteries in your heart?
21. Are you visiting a neurologist for problems associated with the arteries in your head?
22. Have you ever sought out additional information on PAD?
 - a. Yes (→ 23)
 - b. No
23. Where did you find this information?

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